Journal of Aging Studies 56 (2021) 100908

Contents lists available at ScienceDirect

Journal of Aging Studies

journal homepage: www.elsevier.com/locate/jaging

"It makes me feel like good inside because I helped him do stuff" – Perceptions of psychological well-being in adolescents providing dementia care

Jennifer Perion, MLS, CHES [*], Victoria Steiner, PhD, April Ames, PhD, MSOH, CIH

The University of Toledo School of Population Health HH 1000c, Mail Stop 119, Toledo, OH, United States of America

ARTICLE INFO

Keywords:
Adolescent carers
Psychological well-being
Family care
Dementia
Intergenerational care

ABSTRACT

According to a 2018 report by the Alzheimer's Association, an estimated 250,000 children help support a family member with dementia, but few studies exist that describe their experience as family carers. This qualitative descriptive study sought to understand the perceived psychological well-being of adolescents who assist with providing care to family members with dementia. Eleven adolescents ages 12 to 17 caring for older non-parental family members with dementia in northwest Ohio participated in one of three focus group discussions. An adult family member was surveyed about family background and level of assistance provided. The data from the two questionnaires were analyzed using descriptive statistics. Focus group transcripts were analyzed using thematic content analysis. Thematic analysis revealed six themes related to psychological well-being: 1) Feeling compassion for the family member; 2) Finding connection through fun, humor, and mutual affection; 3) Helping even though it is not always pleasant; 4) Feeling good inside about helping family "do stuff"; 5) Believing no one can do it like family; and 6) Reflecting that it is just something that they do. The findings of this study provide new insight into adolescents' experiences of dementia family care and how it affects their psychological well-being. An examination of the themes suggests that secondary caring roles were mostly positive in nature and may help adolescents forge closer family relationships, find opportunities for personal growth and development, and overcome challenges to grow more confident. These findings may also suggest ways to include adolescents in family care as a means of positive growth opportunities.

Introduction

An estimated 53 million Americans provide informal, unpaid care to an adult age 50 or older, assisting with bathing, dressing, and eating, in addition to duties that professional carers traditionally perform, such as wound care or administering intravenous medications (Koepp, Snedden, & Levine, 2015; National Alliance for Caregiving & AARP Family Caregiving, 2020; Reinhard, Levine, & Samis, 2012). In most cases, care is provided by one adult who takes charge of care coordination (Alzheimer's Association, 2020; National Alliance for Caregiving & AARP Family Caregiving, 2020). Many primary carers (about 60%) are also aided by other family members who serve secondary roles such as providing respite care; assisting with activities of daily living and medical care; and helping with non-care duties such as housework and chores (Fruhauf & Orel, 2008; National Alliance for Caregiving/Alzheimer's Association, 2017).

The majority of care provided to the 5.8 million older adults with dementia in the United States comes from family and friends (Alzheimer's Association, 2020). Because modern families take many forms, including single-parent, multi-career couples or grandparent-grandchild households, dementia care often includes children and adolescents (Alzheimer's Association, 2018; Taylor & Quesnel-Vallee, 2017). It is estimated that as many as 250,000 children under the age of 18 provide assistance with dementia care for a family member (Alzheimer's Association, 2018). Youth carers, especially those living with the care recipient, have reported significantly higher levels of anxiety or stress symptoms compared to their peers (Cohen, Greene, Toyinbo, & Siskowski, 2012). Children serving in family care roles may also be more likely to experience depression and behavioral issues, and have greater difficulties completing schoolwork (Kavanaugh, Stamatopoulos, Cohen, & Zhang, 2016; National Alliance for Caregiving, 2005). Adolescents providing care to family members have also expressed frustration

---

[*] Corresponding author.
E-mail addresses: Jennifer.Perion@rockets.utoledo.edu (J. Perion), Victoria.Steiner@utoledo.edu (V. Steiner), April.Ames@utoledo.edu (A. Ames).

https://doi.org/10.1016/j.jaging.2020.100908
Received 1 February 2020; Received in revised form 18 November 2020; Accepted 19 November 2020

related to social restrictions associated with those duties (Williams, Ayres, Specht, Sparbel, & Klimek, 2009).

Most literature related to dementia family care focuses on adult carers, but a few research studies have investigated the perspective of adolescents. Some of these studies discuss the ways that family connections change for adolescents who assist with dementia care. In a mixed methods study with 145 grandchildren age 14 to 21 years old, about a third of the participants (36.6%) reported a worsening in the grandparent/grandchild relationship since the development of dementia and about half (49.7%) indicated reduced emotional closeness (Celdrán, Villar, & Triadó, 2012). Other research suggests that family involvement in dementia care can strengthen family relationships. Interviews with 20 dementia carers with an average age of 18 years suggest that exposure to caregiving duties at a young age can foster greater feelings of family inclusion and closer family relationships (Beach, 1997). In a qualitative study that utilized telephone interviews, researchers investigated the contributions made by 29 adolescents whose parents cared for an older family member with dementia and found increased levels of affection between themselves and their grandparents, resulting in greater motivation to help (Hamill, 2012). Similar findings were reported in a secondary analysis of data from a survey of 138 adolescents, 14 to 24 years of age, who expressed closer family ties and an appreciation for the importance of family support (Celdran, Triado, & Villar, 2009).

Other studies have examined how adolescents are affected by the challenges of dementia care. Thirty-four grandchildren age 7 to 29 years of age were interviewed to learn whether young grandchildren (< 18 years) reported different care experiences than adult grandchildren (18 years or older) (Fruhauf & Orel, 2008). The findings revealed that the younger grandchildren experienced more frustration and fear associated with their care responsibilities than the adult grandchildren (Fruhauf & Orel, 2008). While care obligations may be trying for adolescents, there is evidence that overcoming challenges can be a positive experience. Adolescents living in the same household with a family member with dementia were more likely to feel that the situation impeded their independence and social opportunities, but also expressed that they felt more mature and compassionate than their peers (Celdrán et al., 2012). Transcripts from previously conducted interviews were also reviewed to identify coping strategies of six adolescents age 7 to 17 who provided help to their parents in caring for a grandparent with dementia (Orel & Dupuy, 2002). The qualitative data analysis revealed positive aspects of caregiving such as a sense of accomplishment through caregiving, closer relationships with family members, and coping skills that might be transferred to other life experiences (Orel & Dupuy, 2002).

These research studies focused on the social and relational effects of dementia care on adolescents, but little is known about the impact this has on the psychological well-being of adolescents who care for a family member with dementia. Psychological well-being entails a number of key factors including the creation of positive relationships with others, personal growth, a sense of purpose in life, mastery over environmental variables, self-acceptance, and autonomy (Ryff & Keyes, 1995). Managing ongoing care 'jobs' with the everyday demands of adolescent life could be challenging and affect adolescents' health. From an international perspective, the U.S. is reported to be in a "preliminary stage" regarding its attention to the needs of young carers due to "limited recognition of the existence of caregiving youth and minimal research coinciding with only a handful of dedicated local services" (Kavanaugh et al., 2016, p. 30). Acknowledging the care roles these adolescents play and supporting their involvement can make the difference between an experience that builds empathy and confidence and one that leads to adjustment or mental health issues. The purpose of the present study was to improve the scientific understanding of the experiences of adolescents who assist with the care of an older family member with dementia, and how their involvement in family care impacts their psychological health and well-being.

Methods

A qualitative descriptive design was utilized to explore the experiences of adolescents who are secondary dementia carers. Focus groups were utilized to encourage open sharing of the family care experience among adolescents. Facilitated discussions are viewed as an effective way to collect data for qualitative research, especially when the goal is to gain knowledge about participant "ideas, interpretations, feelings, actions and circumstances" about a phenomenon (Stalmeijer, McNaughton, & Van Mook, 2014, p. 924).

Participants

Following University of Toledo Institutional Review Board approval, recruitment of participants was conducted. Adolescents between 12 and 17 years of age in northwest Ohio who were helping provide care for a non-parental family member over the age of 65 with dementia were included in the study and participated in one of three focus groups. Individuals whose primary language was not English were excluded to reduce communication barriers during the focus group sessions.

Recruitment strategy

The investigators were mindful that families who utilize support programs such as the local Alzheimer's Association may be very different than families who do not, especially if the care structure includes children. After careful consideration, the decision was subsequently made to utilize a marketing research firm, which recruits focus group participants for a variety of purposes including marketing research, product testing and academic research projects. Using the firm for recruiting provided a greater likelihood of reaching families who have diverse experiences and may or may not use programs or services designed for dementia. The marketing research firm was also selected because the staff have experience in research design and maintain a database of individuals who have already indicated an interest in research participation. Because of the intended purpose of the database, the firm uses a variety of methods to enlist individuals including advertisements, kiosks in shopping centers and mailers to ensure that membership reflects the diversity of the region. For this study, an initial email invitation was sent to all 8230 individuals in the database to solicit interest. From that initial invitation, 1347 individuals responded with interest and completed the online screening survey. The online screening survey described the project and asked whether the interested individuals cared for a person with dementia and were aided by an adolescent over the age of 12. While interest in participation was high, the majority of respondents were excluded from the study because they did not meet the inclusion criteria.

Seventeen of the respondents met the study eligibility criteria and received a follow-up telephone call. The telephone screening involved a call to adult respondents, who were asked whether they cared for a family member with memory problems, cognitive issues, or dementia, and were assisted by an adolescent. If the adolescents were providing one-on-one care for a non-parental family member either alone or with someone else, the adults approached the adolescents about participating in a focus group. Five adults and/or corresponding adolescents were considered not eligible after the telephone screening, one declined to participate, one agreed and then cancelled, and one adolescent was recruited but did not show up for the focus group, resulting in nine adolescent participants. Two additional adolescents were recruited by the firm through social media and contacting local aging service organizations. It is not known which of these specific recruiting efforts resulted in the addition of the two participants. The adult carers were only asked to complete a supplemental questionnaire about their family. If these adults were not the individual authorized to sign a parental consent, a parent was contacted as well, potentially resulting in three forms of written informed consent: adult consent, parental consent and adolescent assent.

Data collection

The focus group sessions were held at the offices of the marketing research firm. After completing a brief questionnaire, the adolescents participated in focus group discussions led by a moderator from the firm with a doctoral degree and experience in behavioral science and research. Effective facilitation design utilizes experienced moderators who know how to manage participation and keep the discussion on track; additionally, using a moderator outside of the project reduces conflicts of interest (Then, Rankin, & Ali, 2014). The investigators had concerns that younger participants might feel less willing to share their thoughts and feelings if placed with older participants, so three small focus groups were formed: one for 12 to 13-year-olds ($n = 2$), one for 14 to 15-year-olds ($n = 5$), and a 16 to 17-year-old group ($n = 4$). The focus group sessions lasted approximately one hour and were videotaped for transcription and analysis. Adult carers completed their questionnaire while the adolescents were participating in the focus groups. The adult and corresponding adolescent were given a total of $100 as a standard compensation.

Measures

Surveys

The adult carers were given a questionnaire to provide background information about the family. Questions asked about the family's and care recipient's demographics, as well as living arrangements, the length of time the adolescent had provided care, and the diagnosis (if any) that the care recipient had received. Based on the Caregiver Assessment of Function and Upset (CAFU) (Gitlin et al., 2005), the adults were also asked about six activities of daily living (ADLs) such as bathing and toileting, and nine instrumental actitivies of daily living (IADLs) such as housework and shopping for the care recipient. For each item, the adults were asked to identify the level of assistance needed by the person with dementia on a 5-point Likert scale ranging from 1 (no help) to 5 (complete help). The adolescent questionnaire contained questions about their demographics such as age, gender, grade level, outside employment, as well as care activities they commonly performed.

Focus group interview guide

The focus group discussions were guided by a semi-structured interview with questions and probes to elicit a description of the adolescents' perceptions of how dementia care influenced their psychological well-being. In developing the questions, the investigators drew from existing literature related to family dementia care and psychological well-being among adolescents. Additionally, two content experts, one in adolescent health and the other in adult family caregiving, reviewed the focus group questions for content validity.

The focus group discussions started with an 'ice breaker' question inviting the group to share their personal definition of memory problems to encourage the adolescents to think about their role as carers. As the focus groups progressed, six questions were explored relating to feelings and perceptions of dementia care. Participants were invited to share something that they liked the best and least about caregiving, discuss something that they wished they could change and why, and what they would tell a friend about dementia care. They were also asked whether the role of carer influenced other parts of their lives and/or contributed to feelings and emotions in the past month.

Data analysis

Descriptive statistics were calculated for the demographic and survey data. Videotapes from the focus group sessions were transcribed verbatim into narrative text. The narrative data were examined using Cresswell (2012, 2013) to guide a thematic content analysis that involved the three investigators reviewing the transcripts independently and then as a group during two day-long meetings. The investigators utilized their knowledge of existing literature to guide the analysis of data, while respecting the importance of allowing the themes to emerge from the rich qualitative data provided by the participants. First, broad ideas were identified and then, through the review process, the ideas were narrowed down to themes that could be discussed and supported through the transcripts and existing literature (Cresswell, 2013; Krueger & Casey, 2009). Discussion continued until the group reached consensus. This process ensured that the final reported themes were trustworthy (Elo et al., 2014).

Results

Demographics

Adolescent Carers

Eleven adolescents participated in the study (see Table 1). The majority were White ($n = 7$), with an average age of 15 years. Only one of the participants lived with his or her family member receiving care. Eight of the adolescents spent between five and 10 h per week helping their family member, and three spent more than 10 h per week providing care. The adolescents who participated in this study served secondary carer roles; none had primary responsibilities for the care of an older adult with dementia.

Care recipients

Based on the questionnaire completed by the adult carers who accompanied the adolescents to the focus group sessions, care was being provided for four grandmothers, six grandfathers, one great-grandfather, an uncle and a great-uncle. Adolescents had spent an average of 27 months as a carer. The majority of the care recipients had received a diagnosis, with Alzheimer's disease/dementias most commonly listed ($n = 9$). One care recipient was diagnosed with vascular dementia and another with cerebral aneurysms. Two adults indicated that a diagnosis had not been made for the memory problems or cognitive issues experienced by their family members. Care recipients had a mean total score of 13 for ADLs (SD 7.34; min/max = 6–30), indicating that they needed little help to perform these activities. The mean total score for IADLs was 31 (SD 10.92; min/max = 14–45), indicating that the care recipients needed moderate to high amounts of help with daily instrumental activities.

Focus group themes

The focus group discussions revealed six themes related to the adolescents' psychological well-being: 1) Feeling compassion for the family member; 2) Finding connection through fun, humor, and mutual affection; 3) Helping even though it is not always pleasant 4) Feeling good inside about helping family "do stuff"; 5) Believing no one can do it like family; and 6) Reflecting that it is just something that they do.

Feeling compassion for the family member

The adolescents expressed feelings such as sadness and empathy toward older family members with memory problems or cognitive issues that suggested a level of compassion for their situations. They recognized that behaviors such as forgetting names or struggling to remember were not the fault of their family member, and they acknowledged the difficulties that memory loss caused. Casey (male, 13) described his feelings: "it kind of makes me upset…not like angry, [it] kinda makes me sad…because he forgets who I am." Jeff (male, 12) agreed: "I mean I like to help people, but it just feels cause it's my family member so it's hard

Table 1
Demographic details of participants.

Pseudonym	Gender	Age	Race	Ethnicity	Grade in school	Self-reported health	Care recipient relationship	Self-reported time as a carer (months)
Casey	M	13	White	Non-Hispanic/ Latino	8	Excellent	Great-grandfather	4
Jeff	M	12	African-American	Hispanic/ Latino	7	Very good	Grandfather	3
Jessie	F	14	African-American	Non-Hispanic/ Latino	9	Very good	Great-Grandmother	12
Allen	M	15	White	Non-Hispanic/ Latino	9	Excellent	Grandfather	24
Sue	F	15	White	Non-Hispanic/ Latino	10	Fair	Uncle/Great-Uncle	72
Tony	M	14	White	Non-Hispanic/ Latino	9	Very Good	Grandmother	36
Joi	F	14	African-American	Non-Hispanic/ Latino	8	Very good	Grandmother	12
Wyatt	M	17	White	Non-Hispanic/ Latino	12	Excellent	Grandmother & Grandfather	36
Allyson	F	16	White	Non-Hispanic/ Latino	10	Good	Grandfather	72
Annie	F	17	African-American	Non-Hispanic/ Latino	12	Very Good	Grandfather	24
Bailey	F	16	White	Non-Hispanic/ Latino	Not in school	Good	Grandfather	2

for me to process that he needs the extra help. I'm not mad that he needs the extra help because I will help him, but it's I just feel sad about it…. If it was somebody else I would care, but I wouldn't feel so sad because it's not my family member." The feelings expressed by Allen (male, 15) suggest that he understood how his grandfather might feel about needing assistance: "I take him out of the shower and get him up off the toilet that's not all that fun…. I mean it's less fun because you see that he doesn't want to be in that mental state and that if he could be, he wouldn't be."

Finding connection through fun, humor, and mutual affection

The participants recognized that their family members with dementia were still capable of having fun with them and enjoying life. Casey (male, 13) enjoyed watching his grandfather flirt with women living in his apartment complex: "He flirts with a lot of old women," which he found "hilarious." Joi (female, 14) enjoyed running errands with her grandmother: "We hang out a lot we go get ice cream and we do …activities and…make runs and stuff…we be having fun." The adolescents conveyed appreciation for playful interactions, even when they were at their expense. Jeff (male, 12) explained, "So he's …asking me that question like a hundred times and I'm like 'okay I just said this. This is how you use it' and he's like 'what?' 'This is how you use it,' 'Say it one more time?' 'This is how you use it.' He's like, 'I'm just playing I heard you the first time.'" Casey (male, 13) recognized the playful banter: "My grandpa does that to me too he plays games with my mind," but he was able to joke and tease back: "I always make my grandpa laugh." Wyatt (male, 17) enjoyed jokes with his grandfather: "he's always trying to crack jokes on everybody."

The participants felt the grandchild/grandparent relationship was important, and affection was bi-directional, which made it easier to deal with the demands of caregiving. Bailey (female, 16) explained, "he cares about us too…we're not just gonna care about somebody who doesn't care about us." When asked how her grandfather showed affection, she responded, "In a lot of different ways. There's not one specific way somebody can show that they care for you…just because he doesn't remember does not mean he doesn't care." Jeff (male, 13) also felt that his relationship with his great-grandfather was important to him: "me and my grandpa have a strong connection because when I was a like baby he used to take me to his house and he used to tell my mom 'I need to teach him the basics of responsibility, respectfulness, and that type of stuff'….I wouldn't be responsible and respectful to older people like I am now."

Helping even though it is not always pleasant

While mostly positive about their responsibilities, the adolescents described some duties they found less enjoyable. Some were related to communication difficulties caused by memory problems or cognitive issues. Wyatt (male, 17) explained, "I think for me it's the amount of repeating and stuff like that comes with telling a story or something. I mean I'll tell a story and then he'll be like, 'alright now say that again'… it gets kind of tiring and you spend a lot of energy telling this long story and then he tells you to repeat it." Jessie (female, 14) shared her frustration: "it's…stressful because I'm so used to telling somebody to do something and they…automatically do it, but you have to repeat yourself over and over to the person."

Intimate care such as toileting and physical activities like heavy lifting, transferring and moving were considered undesirable jobs by the participants. Jessie (female, 14) expressed her distaste for physical activities: "I don't change her, my other grandma does, but I have to help cause she's heavy, so I have to roll her on her side, and I don't like doing that cause she's just too heavy." There were some duties she refused to undertake: "she has gangrene in her foot which I'm not touching." Allen (male, 15) described his experience helping his obese grandfather: "for the past months I became a plumber cause he…is so big that he broke the seat of the toilet…to be honest it's not fun to get down there and clean it up…." Being called upon to help his grandmother with his grandfather's care during the night was also difficult for Allen: "sometimes when I get tired at night and she calls me in the middle of the night while I'm asleep or something I just get irritated…I don't let her know it's irritating; I just get up and do it."

The adolescents also found it difficult to deal with times their family member with dementia expressed anger or depression. "He gets frustrated with himself when he misplaces things, so I just have to be there to reassure him that it's not his fault or just help him find whatever it is he is looking for," explained Annie (female 17). She described how frustration impacted her grandfather's moods: "I just think that he is frustrated with himself because he doesn't start yelling or anything he's just really down or negative at the time." Jessie (female, 14) described her grandmother's emotional state: "my grandma she just lays in her bed … being grumpy and depressed. Grumpy and depressed."

Feeling good inside about helping family "do stuff"

Several of the participants referred to their care responsibilities as similar to typical grandparent/grandchild activities such as "hanging out", watching television or keeping their older relative company. Annie (female, 17) described her usual responsibilities helping care for her grandfather: "I sit there, I bring my homework. If my grandma needs me to do something around the house, I do that, if she needs help with cooking I do that." Sometimes Annie provided respite for her grandmother: "she's really into church so whenever she goes there or she's out at the store… I'll go over there for like a couple hours, but it's not really long." Several of the adolescents described duties such as household and yard chores like Tony (male, 14): "I just mow the lawn or do yard work or help around the house and clean." Joi (female, 14) found it easier to do things for her grandmother: "I help her do stuff around house cause she when she bend over…I gotta help her back up so she get stuck and she call my name and I have to get her back up. So, I just clean-up for her instead of her doing it." Simply hanging out with his grandparents was important to Wyatt (male, 17): "it may not be …for an entire night or something; I'll only be there for a few hours just saying hi, telling them everything that's new. They like hearing the stories from me and all of the things that I'm involved with and everything …that brings them joy."

While not all of the care tasks assigned to the adolescents were especially difficult, the adolescents recognized their roles as helpers, and expressed a sense of satisfaction and pride in their contributions. Jeff (male, 12) explained: "I love to care for people…I like to help people and so…it makes me feel good inside because I helped him do stuff." This feeling was echoed by Annie (female, 17): "I enjoy helping them. It always feels good helping someone that needs help." One of the things that made Jeff (male, 12) feel good was refusing payment for his assistance "I feel good because my grandma usually tries to pay me. I say no to it." Casey (male, 13) agreed, explaining: "It's rude. For helping a family member you're basically being greedy by taking the money that they could be spending on extra like medicine for them."

Believing no one can do it like family

The adolescents expressed a sense of obligation to help family members. Wyatt (male, 17) explained that his family decided against using paid carers: "my family we've talked to them [grandparents] about having somebody come in and doing that stuff for them, but they don't feel comfortable with them being strangers and stuff and them not knowing them so they just like us coming by and you know doing all those kind of things for them." This sentiment was similar to Allen's (male, 15): "It's just something you would do…we take care of each other… we take care of our own, we don't let people take care of us." When asked about using outside help, Allen (male, 15) described his reservations: "I just think it would be different…cause family takes care of family no one treats you better than family. I just couldn't see someone else coming in that doesn't know you and doing those type of things as well as we could. Even though they have the training I just don't feel like he would feel as safe." Tony (male, 14) agreed: "Yeah, they may not do it better, but…they'd feel safer with me doing it cause they trust me and they know who I am." Sam (female, 15) explained: "it's just the familiar faces are nice and then if it's another caregiver from a different business or something like that then it kind of makes him upset…".

Reflecting that it is just something that they do

The participants were asked if they felt that they were missing out on things because they were expected to help with their family member. Jeff (male, 12) indicated that sometimes he missed participating in sports events for his school: "I missed a hockey game…but he needed it because he had to go to the doctor for surgery." Sue (female, 15) spent her entire summer out of state helping her grandmother, and this was difficult for her: "I was kinda tired after spending the entire summer. Normally I'm there for just a month but not being able to go out and do stuff and having a small amount of time to do things like shopping…." Joi (female, 14) felt less restricted: "Sometimes on the weekend my friends ask me to go somewhere with them and I have to stay with her [grandmother] because she get…emotional cause she think don't nobody want to help her. She down, so I just stay with her instead of going." This didn't bother Joi much because "I know on another weekend I can try again like the week after that one." Jessie (female, 14) felt unconcerned about lost time because she was able to participate in sports: "I play sports so in the summer I can't be there all the time mostly like on weekdays so on the weekends…I go out there." Allen (male, 15) didn't feel like he was missing out on the things he wanted to do, explaining, "I didn't feel with sports it was that hard to do. Especially with two-a-days you go there at five make coffee then leave for practice and come home at noon make them lunch and then leave again."

Perhaps because they did not find it burdensome or socially restrictive, the adolescents indicated that caregiving felt like a normal part of life and rarely came up in discussions among members of their social circles. When asked if they talked about their care responsibilities with friends or classmates, Allen (male, 15) responded, "No, I don't think anyone knows." The moderator asked why no one was aware of his grandfather, to which he replied, "It's just something that I do, it's not something I tell people…I mean it's not that I'm embarrassed it's just not something I talk about." Tony (male, 14) agreed, adding, "It's just I never really think about it…it's just what we do." Annie (female, 17) had similar feelings: "I mean if someone asks and I'll answer, but it's not something I just go around talking about I guess." Bailey (female, 16) indicated that many of her friends met her grandparents, but she didn't tell them about her grandfather's memory problems. Jeff (male, 12) and Casey (male, 13) both indicated that they frequently shared information about their grandfathers with their friends.

Discussion

The focus group participants, ranging in age from 12 to 17, revealed common experiences related to caring for a non-parental family member with memory problems. All of the adolescents served as secondary carers and performed a variety of tasks from keeping a relative company to providing medical care. The findings of this study begin to elucidate the impact that dementia family care has on the psychological well-being of adolescents. The information shared by the participants provides insight into the way that adolescents perceive care roles, and how those roles impact their personal sense of well-being within the context of their lives. Although the adolescents expressed both positive and negative aspects of dementia care, the analysis of the data points to mostly positive influences on their well-being.

After the themes were identified, they were consequently drawn to the dimensions of the Ryff Well-being Theory to provide context for the phenomenon of well-being. Ryff's Theory was developed using a multigenerational and multi-dimensional approach to find the factors most likely to indicate the presence of psychological well-being in individuals (Ryff, 1989) and consists of six dimensions: Positive relations with others, Personal growth, Purpose in life, Environmental mastery, Self-acceptance, and Autonomy (Ryff, 1989; Ryff & Keyes, 1995).

While Ryff's Well-being Theory was not included in the development or design of the present study, its application to the findings provide a way to understand how the perceptions of care may contribute to psychological well-being among the population under study. Specifically, the themes that emerged from the data can be related to four of Ryff's six dimensions: positive relations with others, personal growth, purpose in life, and environmental mastery.

Ryff's Well-being Theory suggests that positive relations with others are evident when individuals have developed relationships that indicate a genuine personal connection (Ryff, 1989; Ryff & Keyes, 1995). The adolescents included in this study expressed compassion for the changes that they saw in their family members. Additionally, they conveyed feelings of affection and warmth for their older family members and cited numerous opportunities for bonding and having fun, supporting findings by other researchers studying care relationships of adult grandchildren (Celdran et al., 2009; Hamill, 2012; Orel & Dupuy, 2002) or the grandchild/grandparent relationship (Celdrán et al., 2012). The themes evident in this study suggest that the adolescents had successfully forged positive relations with their family members despite the presence of dementia (Beach, 1997; Hamill, 2012; Ryff, 1989; Ryff & Keyes, 1995).

Supporting previous studies, there were times when the adolescents in this study felt frustrated or irritated about their care duties (Fruhauf & Orel, 2008). However, the majority of the adolescents communicated their ability to overcome those feelings and continued lending a hand. Ryff's Theory suggests that the dimension of personal growth is achieved by embracing new experiences and developing higher levels of competency and maturity, which in turn presents opportunities for a sense of achievement and independence (Ryff, 1989). The ability to overcome frustration or distaste for jobs suggests that providing care created a sense of achievement and pride among the adolescents that is necessary for personal growth (Ryff, 1989; Ryff & Keyes, 1995).

The focus group discussions suggested that the adolescents felt happiness and a sense of belonging as a result of their care duties, which supports previous research regarding the positive aspects of caregiving (Beach, 1997; Hamill, 2012; Orel & Dupuy, 2002). As in other studies, many of them felt strongly about the importance of family obligations in providing support to their family members (Celdran et al., 2009; Hamill, 2012). As a construct of well-being, recognizing that there is a purpose in life and that one has a place in their world is important to the development of optimal mental health, and a sense of meaningfulness through "a clear comprehension of life's purpose, a sense of directness, and intentionality" (Ryff, 1989, p. 1071).

Environmental mastery as a dimension of well-being relates to the ability of an individual to control and manipulate outside factors to create a positive and fulfilling environment (Ryff, 1989). When present, environmental mastery reflects self-efficacy, which is important to positive mental health and to the development of a positive personal environment (Ryff, 1989; Ryff & Keyes, 1995). The adolescents in this study expressed a level of control over their care duties, from refusal to perform unsavory jobs to ensuring that there were opportunities for social engagement. Additionally, the adolescents indicated a sense of competence in their ability to perform care duties and provide assistance to their family members. The adolescents were mostly unconcerned about the time that they spent caring for their family member and indicated that they still found time to spend with friends, participate in sports and attend to their schoolwork. This is contrary to previous research that suggests that care duties create problems such as behavioral and school performance issues for adolescents (Kavanaugh et al., 2016; National Alliance for Caregiving, 2005).

Limitations

The type of carer who agreed to take part in the study may have been affected by the recruitment of individuals previously indicating an interest in participating in focus groups and receiving financial compensation. The adult questionnaire asked about the respondent's education and income, but not all of the adolescents lived in the same household as the adult. This made it difficult to determine to what extent socioeconomic factors influenced the carer experience and responses of the focus group participants. The range of ages among participants was large, considering the developmental processes that adolescents experience. Finally, the format of the focus groups with an adult moderator and a co-ed group of adolescents may have influenced the responses that participants provided. While every attempt was made to encourage open discussion, the study participants may have felt a need to present caregiving in a positive light, especially because the discussions were about family members. The fact that participants did share some negative experiences and frustrations suggests an attempt at honesty, but it is not possible to know if the participants practiced a certain degree of censorship in their responses.

Conclusion

This qualitative descriptive study solicited the perceptions of adolescents between the ages of 12 and 17 about their role as secondary carers for a non-parental family member with memory problems. After conducting a thematic content analysis of focus group data, six themes emerged related to their family care experience which were linked to constructs of Ryff's Well-being Theory. The adolescents expressed thoughts and feelings that suggest that their care experiences resulted in positive relations with others, personal growth, the development of purpose in life, and environmental mastery.

The findings of this study suggest areas for increased research, as well as support and education among adolescent carers. Although the adolescents in this study expressed feelings of sadness and frustration, the discussions did not support prior reports that providing care causes high levels of stress. It is possible that because the majority of the adolescents viewed their role as secondary rather than as the primary carer, they were removed from the risks of negative emotions. Future research could explore the perceptions of adolescents who serve in primary roles. Additionally, studies could examine the influence that socio-cultural and economic factors such as cultural background, socio-economic status, family size and history, and social support networks have on adolescents' care experiences and the subsequent impact on their psychological well-being.

The opportunity also exists to use the knowledge gained from this study to encourage families to include adolescents in family care tasks. Because many of the adolescents had positive feelings regarding their care duties including feeling good about helping, having fun with family, and recognizing the value of family, programs that teach entire families to participate in care may both alleviate primary carer overload, and provide opportunities for growth and learning experiences for younger family members as well as disrupt the exclusively pejoratively views of dementia and ageism more broadly that prevail in American society.

Funding

This work was supported by the National Institute for Occupational Safety and Health through the Pilot Research Project Training Program of the University of Cincinnati Education and Research Center [grant number T42OH008432].

Declaration of Competing Interest

None.

Acknowledgement

We thank Jeanna Tran, MLS (University of Toledo) for assisting with data management and Dr. Kimberly McBride (University of Toledo) for providing an astute review of this manuscript.

References

National Alliance for Caregiving, & AARP Family Caregiving. (2020). Executive summary*:* Caregiving in the United States 2020. Retrieved from https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316_ExecSum_CaregivingintheUS_WEB.pdf.

Alzheimer's Association. (2018). *2018 Alzheimer's Disease Facts and Figures*. Retrieved from. *13* pp. 367–429). https://www.alz.org/media/homeoffice/facts%20and%20figures/facts-and-figures.pdf.

Alzheimer's Association. (2020). 2020 Alzheimer's Disease Facts and Figures. Retrieved from https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf.

Beach, D. L. (1997). Family caregiving: The positive impact on adolescent relationships. *Gerontologist, 37*(2), 233–238. https://doi.org/10.1093/geront/37.2.233

Celdran, M., Triado, C., & Villar, F. (2009). Learning from the disease: Lessons drawn from adolescents having a grandparent suffering dementia. *International Journal of Aging & Human Development, 68*(3), 243–259. https://doi.org/10.2190/AG.68.3.d

Celdrán, M., Villar, F., & Triadó, C. (2012). When grandparents have dementia. *Journal of Family Issues, 33*(9), 1218–1239. https://doi.org/10.1177/0192513x12443051

Cohen, D., Greene, J., Toyinbo, P., & Siskowski, C. (2012). Impact of family caregiving by youth on their psychological well-being: A latent trait analysis. *The Journal of Behavioral Health Services & Research, 39*(3), 245–256. https://doi.org/10.1007/s11414-011-9264-9

Cresswell, J. (2012). *Qualitative Inquiry & Research Design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: SAGE Publications, Inc.

Cresswell, J. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Thousand Oaks, CA: Sage.

Elo, S., Kaariainen, M., Kanste, O., Polkki, T., Utriainen, K., & Kyngas, H. (2014). Qualitative content analysis: A focus on trustworthiness. *SAGE Open, 4*(1). https://doi.org/10.1177/2158244014522633

Fruhauf, C. A., & Orel, N. A. (2008). Developmental issues of grandchildren who provide care to grandparents. *International Journal of Aging and Human Development, 67*(3), 209–230. https://doi.org/10.2190/AG.67.3.b

Gitlin, L. N., Roth, D. L., Burgio, L. D., Loewenstein, D. A., Winter, L., Nichols, L., & Martindale, J. (2005). Caregiver appraisals of functional dependence in individuals with dementia and associated caregiver upset: Psychometric properties of a new scale and response patterns by caregiver and care recipient characteristics. *Journal of Aging and Health, 17*(2), 148–171. https://doi.org/10.1177/0898264304274184

Hamill, S. B. (2012). Caring for grandparents with Alzheimer's disease: Help from the forgotten generation. *Journal of Family Issues, 33*(9), 1195–1217. https://doi.org/10.1177/0192513x12444858

Kavanaugh, M. S., Stamatopoulos, V., Cohen, D., & Zhang, L. (2016). Unacknowledged caregivers: A scoping review of research on caregiving youth in the United States. *Adolescent Research Review, 1*(1), 29–49. https://doi.org/10.1007/s40894-015-0015-7

Koepp, G. A., Snedden, B. J., & Levine, J. A. (2015). Workplace slip, trip and fall injuries and obesity. *Ergonomics, 58*(5), 674–679. https://doi.org/10.1080/00140139.2014.985260

Krueger, R. A., & Casey, M. A. (2009). *Focus groups: A practical guide for applied resesarch* (4 ed.). Thouand Oaks, CA: Sage Publications, Inc.

National Alliance for Caregiving. (2005). *Young caregivers in the U.S.: Findings from a national survey*. Retrieved from http://www.caregiving.org/data/youngcaregivers.pdf.

National Alliance for Caregiving/Alzheimer's Association. (2017). *Dementia Caregiving in the U.S.* retrieved from Bethesda, MD http://www.caregiving.org/wp-content/uploads/2017/02/DementiaCaregivingFINAL_WEB.pdf.

Orel, N., & Dupuy, P. (2002). Grandchildren as auxiliary caregivers for grandparents with cognitive and/or physical limitations: Coping strategies and ramifications. *Child Study Journal, 34*(4), 193–214.

Reinhard, S., Levine, C., & Samis, S. (2012). Home alone: Family caregivers providing complex chronic care. Retrieved from Washington, D.C http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf.

Ryff, C. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology, 57*(6), 1069–1081.

Ryff, C., & Keyes, C. (1995). The structure of psychological well-being revisited. *Journal of Personality and Social Psychology, 69*(4), 719–727.

Stalmeijer, R. E., McNaughton, N., & Van Mook, W. N. (2014). Using focus groups in medical education research: AMEE guide no 91. *Medical Teacher, 36*(11), 923–939. https://doi.org/10.3109/0142159X.2014.917165

Taylor, M. G., & Quesnel-Vallee, A. (2017). The structural burden of caregiving: Shared challenges in the United States and Canada. *The Gerontologist, 57*(1), 19–25. https://doi.org/10.1093/geront/gnw102

Then, K., Rankin, J., & Ali, E. (2014). Focus group research: What is it and how can it be used? *Canadian Journal of Cardiovascular Nursing, 24*(1), 16–22.

Williams, J. K., Ayres, L., Specht, J., Sparbel, K., & Klimek, M. L. (2009). Caregiving by teens for family members with Huntington disease. *Journal of Family Nursing, 15*(3), 273–294. https://doi.org/10.1177/1074840709337126